

Questions and Answers about the cancer Human Biobank (caHUB)

This fact sheet answers common questions about donating to the cancer Human Biobank—or caHUB. You may want to consider whether to provide tissue samples and medical information to caHUB. It may help you to talk to family, friends or medical caregivers before making your decision.

Glossary Of Important Terms

Biobank – A place where samples of human tissue, blood, and other specimens are collected and stored for future use in medical research. Many biobanks are used to study how genes affect disease.

cancer Human Biobank (caHUB) – a biobank created by the National Cancer Institute (NCI) to be a national resource for research on cancer and other diseases.

Genes – the part of cells that contains instructions for how our bodies work. Genes carry information about traits that run in families, like brown eyes or blue eyes. Genes may partly explain why some people are more likely to get diseases like cancer, diabetes, and asthma.

Genetic research – studies of how traits passed down in families affect health and illness. Studying genes helps researchers find new ways to treat different diseases.

Samples – small amounts of tissue, liquid, or cells that come from the human body. Samples can include:

- Fluids such as blood, saliva (spit), and urine
- Tissue (small amounts removed during surgery)
- Normal and diseased cells
- Other body materials like skin, bone, hair, and nails

Answers to common questions

Why are samples important for research?

Letting researchers study your samples may help find new and better treatments for cancer and other diseases. Researchers use samples to look for ways to prevent, find, or treat health problems—as in Example 1.

Studying samples helps researchers:

- Learn how cells work
- Find causes or signs of disease
- Make new drugs and tests
- Find signs about who is more likely to get a certain disease or respond well to a certain treatment
- Tell if a type of treatment is likely to work

Example 1

Researchers studied thousands of breast cancer samples. This helped them:

- find out that 1 in 4 breast cancers carried extra copies of a certain gene;
- make a test to identify breast cancers that carried the extra gene copies; and
- make treatments that helped women with these types of breast cancers live longer.

This was only possible because thousands of women gave their samples for research.

How will the caHUB collect samples for research?

The caHUB works with institutions like [INSERT INSTITUTION NAME] to collect samples from people for research. Even samples from people who are healthy or do not have cancer are still very helpful for research.

Some samples are collected during routine medical procedures. Your doctor removes samples as part of your medical care. When you give permission, samples that don't need to be kept for your medical care can be used for research. A doctor at [INSERT INSTITUTION NAME] will determine whether all of your samples need to be kept for your medical care, or if some could be donated for research.

Other samples are collected ONLY for research. If you give permission, [INSERT INSTITUTION NAME] may take urine, blood, or other samples just for research purposes. These samples are separate from your medical care.

Why does the caHUB collect other information along with samples?

Studying medical information related to samples is an important part of most research. It helps researchers figure out why drugs or other treatments work for some people but not for others, as in Example 2 below.

[INSERT INSTITUTION NAME] will collect information from sample donors' medical records and send it without a name or other identifying information to the caHUB. This information may include:

- Age, sex, ethnicity, height, and weight
- Medical history, like history of high blood pressure
- Family history, like history of cancer
- Smoking history
- Diagnosis of cancer or another illness
- How well certain treatments have worked

Example 2

Some people will have bad reactions to certain drugs because of their particular genes. Researchers studying many people's samples and medical information can predict who might have a bad reaction to certain drugs. If someone is likely to have a bad reaction, this information could be put in his or her medical record. That way, doctors would know not to give that person certain drugs that could make him or her sick.

What will the caHUB be used for?

Samples and information stored in the caHUB will be used to study cancer and other diseases such as diabetes, heart disease and mental health disorders. Some of the research will look at how genes affect health and illness. The caHUB will only be for research and won't store samples for organ transplants or blood transfusions. Some of the questions researchers may study are:

- Who is at risk for getting a disease and why?
- Who may have more side effects from treatment?
- How does a disease affect different age or ethnic groups?

Do donors get to choose how their samples and information are used?

No. If you donate to the caHUB, you cannot choose how your samples and information will be used in research. Donors do not get to pick which research studies use or don't use their samples.

How long will the samples and information in the caHUB be used?

There is no limit on how long the caHUB can store and use the samples and information it collects. The caHUB will keep and continue using all samples unless a donor asks to have them destroyed or the biobank closes.

Anyone who donates to the caHUB can change their mind about letting researchers use their samples and information. If a donor changes their mind, any samples left in the bank will be destroyed or possibly returned to the hospital that collected them.

Donors who change their mind should know that:

- Samples and related medical information already given to researchers or used in research studies cannot be returned
- Research results that used their samples and information cannot be changed or stopped

Will caHUB send donors results of research done on their samples?

No. If you donate to the caHUB, caHUB will not send you personal results of research on your samples. Research takes a long time and may not help patients for many years. Samples are also needed from thousands of people before research leads to results that are useful. Any useful results will be shared with the public. In the very unlikely event that caHUB researchers discovers something important about your personal medical condition, caHUB will contact [Institution] so that [Institution] can explain the results to you.

What happens if research using caHUB samples leads to important new discoveries?

All caHUB study results will be shared with other scientists and the medical community. The data will be made available for future research use and for the development of medical treatments and tests. The caHUB is not designed to share profits with donors if any research discoveries result in drugs or other products that are sold.

How do I sign up to donate to the caHUB?

Staff at [INSERT INSTITUTION NAME] will explain how the caHUB works and talk to you about donating. They will also ask you to read a consent form that describes what will happen if you say yes. If you decide you want to donate, you must sign the consent form to be part of the caHUB. If you decide not to donate, your decision will not affect your medical care or your ability to participate in other research studies.

What if I have more questions?

If you have any questions, talk to your doctor or nurse, or call [PHONE NUMBER ON CONSENT FOR INFORMATION ABOUT STUDY]. You can also visit the caHUB web site at

<http://cahub.cancer.gov/>

Thank you for learning more about the caHUB!